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**Are we making progress on communication with people who are near the end of life in
the Australian health system? A thematic analysis**

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Abstract

Initiating end-of-life discussions with patients is often delayed or avoided altogether by health care practitioners even in light of imminent death. This continues despite the availability of guidelines and conceptual frameworks on how to communicate prognoses at end-of-life. We surveyed health care practitioners to elicit their exposure to and confidence in end-of-life discussions and to better understand factors that enable or challenge the initiation of discussions in Australian health care settings. Thematic analysis identified that end-of-life discussions could be emotionally burdensome for health care practitioners but were regarded as valuable. Effective communications were challenged by conflict with families and between health care practitioners as to appropriate care goal transition, and by prognostic uncertainty. Communication skills appeared to be developed more from experience, and beneficial strategies such as role-play and mentoring particularly for younger nurses and doctors were identified. Specific training in end-of-life communications should target undergraduates and new health care practitioners

Background

Initiation of end-of-life (EoL) discussions (i.e. communication of poor prognosis, need for advance care planning (ACP) including an advance care directive (ACD) and possible change or discontinuation of treatment) with patients are often delayed or avoided altogether even in light of imminent death (Sullivan et al., 2007). Physicians have less confidence in these conversations than when discussing other medical issues (Moss, Demanelis, Murray, & Jack, 2005; Sulmasy, Sood, & Ury, 2008), yet a hierarchy of authority compels physicians, rather than nurses or other staff, to initiate EoL discussions in Australia (Sellars et al., 2017).

A variety of underlying factors have been identified to explain the reluctance of physicians to discuss end of life issues: low confidence and lack of appropriate communication skills in delivering bad news (Fallowfield, Jenkins, & Beveridge, 2002; Orgel, McCarter, & Jacobs, 2010); burnout and work related stress and dissatisfaction among health professionals associated with insufficient communication training (Anstey, Adams, & McGlynn, 2015; Ramirez et al., 1995); the stress associated with patients who are terminally ill (Wilkinson, Perry, Blanchard, & Linsell, 2008); inaccuracy in estimating the time to death (Christakis & Lamont, 2000); physician's attitudes towards patient or surrogate decision-makers (Visser, Deliens, & Houttekier, 2014); and lack of adequate or formal end-of-life care and communication training in medical schools (Anstey, et al., 2015; Levinson, Lesser, & Epstein, 2010).

In particular, a lack of training in undergraduate courses has resulted in many physicians reporting discomfort in the delivery of breaking bad news to patients (Quinn et al., 2009). This inadequate preparation of junior doctors to deal with patients, bereaved families, and their own emotional feelings in relation to patients' deaths (Sullivan, Lakoma, & Block, 2003) occurs despite the literature highlighting comprehensive national guidelines and conceptual frameworks on how to communicate prognoses at the end of life (Baile et al.,

2000; Brighton et al., 2018; Clayton et al., 2007; National Institute for Health and Care Excellence, 2015; Villagran, Goldsmith, Wittenber-Lyles, & Baldwin, 2010). Additionally, physicians working in intensive care units (ICU) often do not engage colleagues in feedback about the inappropriate escalation of care (Anstey, et al., 2015).

When EoL discussions are inadequate, patient and family care can be compromised. To prevent futile treatment, effective communication needs to take place across the system and include collaborative discussions within and across medical teams just as it does with patients and families (Lingard, 2009). End-of-life communication can be complex and is negotiated uniquely for each context and situation (Gallois et al., 2015). It needs to reconcile the expectations and personal beliefs of patients and families, with those of the clinician and the treating team (Hewitt, Watson, & Gallois, 2013), and agreement needs to be reached within a system that determines the boundaries of treatment possibilities (Institute of Medicine (US) Committee on Care at the End of Life, 1997).

In consideration of the continued prevalence of inadequate discussions about EoL, we conducted a survey to investigate reasons for the poor communication. We aimed to identify barriers to and enablers for EoL discussions and to use the findings to inform the potential development of educational interventions to enhance communication. The objectives were to:

1. Assess respondents' level of exposure to and confidence in initiating EoL conversations;
2. Identify factors influencing their confidence in those discussions; and
3. Propose training strategies for addressing nominated barriers.

The aim of this qualitative research was to complement our quantitative survey data by providing a greater understanding of the experiences and views of clinicians when engaging in EoL discussions.

Methods

We conducted a 14-item online survey but also offered face-to-face interviews to those without ready access to internet. The instrument was designed *de novo*, based on our reading of the literature and informed by local need. It consisted largely of multiple choice sections and some open-ended questions posed throughout the survey (Appendix A). The survey was pilot-tested and refined by three nurses and one doctor until agreement was reached on readability, concept clarity, user-friendliness and duration. Senior and junior staff working in Australian intensive care units, oncology, palliative care (PC) and emergency departments (ED) were eligible to participate, as were aged care and primary care nurses and doctors. We defined senior staff as those who had supervisory responsibilities such as staff specialists and nurse consultants. The survey was launched and promoted at three medical conferences and via clinical network emails to colleges and societies, as well as Twitter, Facebook and through advertisements in nurses' magazines.

Ethics approval was granted by the University of New South Wales Research Ethics Advisory Panel (project #HC15177). Participation was acknowledged as consent.

Participants provided a large amount of data which were analysed thematically (by ST) through an inductive/data driven approach, according to established guidelines (Braun & Clarke, 2006). A thematic approach to analysing qualitative survey data has been effective for other researchers (Barnieh et al., 2014; Treiber & Jones, 2010). Themes were not defined a-priori but were identified after the initial readings of the data. The data were first read by one author (ST) several times, to become familiar with the content and generate an initial idea of themes. To ensure rigor in the analysis we then engaged a second qualitative researcher (MK) to undertake the same iterative approach of reading and re-reading the data, checking the coding frame and its subsequent revisions for coherence, and checking and assisting with theme identification and labelling. The final thematic structure was then reviewed by another research team member (MC) who checked theme coherence and integrity. Any disagreements

between the authors were resolved by consensus with the wider authorship. Lastly, a selection of powerful and compelling examples was selected, with context, to represent each theme. Thematic analysis also involved identifying and reporting on discrepant information and we used NVivo 10®.

Results

Our survey was completed by 408 respondents, but data from 40 respondents were excluded as they did not reside in Australia or were not in the target occupational groups. A further eight respondents were excluded because they did not deal with patients at the end of life. The age/gender distribution of respondents aligned with that of the health workforce in Australia, where the majority are nurses (36 nurses for every doctor), female, with a third of the doctors being specialists, and two thirds of the nurses aged 40 years and above (Australian Bureau of Statistics, 2013).

Most respondents only completed the multiple choice sections of the survey, but at least one in five participants provided thoughtful responses in considerable detail to the free text questions. The quantitative cross-sectional results are reported elsewhere (Australasian Journal on Ageing, under review, 2018). Qualitative response options were provided for six questions around comfort and confidence with EoL discussions, barriers and enablers to EoL discussions, and educational strategies. The final question in the survey asked participants to comment on anything else they felt was important. Some open-ended questions received up to 138 responses.

As an organising structure, we retained the three main survey categories where qualitative responses could be provided. We analysed each of these categories thematically. Themes were organised under “Experiences with EoL discussions”, “Challenges to EoL Discussions”, and “Facilitators of EoL Discussions”.

Experiences with EoL Discussions. This was described by a single key theme that highlighted the emotional commitment of clinicians when engaging in EoL discussions with patients and their families.

Emotional commitment. We asked respondents if they could describe some of their experiences with EoL conversations. Many described these as rewarding but also that they could be emotionally burdensome. “I felt comfortable but it can also be emotionally exhausting” (specialist). A nurse said: “I accept that it is part of my job but still have some degree of discomfort at times”.

There was a sense of emotional attachment occurring in some of these discussions where a nurse said: “some can relate to your own personal experiences which can impact more”. A specialist similarly noted: “some impact more significantly especially if the patient is young but overall it is really part of my job”. Moreover, the emotional impact did not always end at the bedside with some respondents reliving their experience for some time: “I find myself reflecting on the situations at times throughout the day and night” (nurse).

Despite the recognition that good EoL discussions were not easy to initiate, their value was consistently identified. A nurse responded with: “I find them difficult to initiate at times, but I also find them rewarding and vital to the patient's care”.

Challenges to initiating end-of-life discussions. There were six key themes that described the qualitative data in this area. Lack of consensus among members of the medical team; Death as medical failure; Care goal transition; Recognising contextual differences with patients and families; Lack of formal training and low confidence; and An unhelpful system.

Lack of consensus among members of the medical team. Many informants highlighted how a reluctance to discuss EoL care was related to a lack of consistent understandings of treatment goals among members of the medical teams. Indeed a specialist said: “there are differing goals of care between treating clinicians”. Some also held a belief

that engaging in EoL discussions implied giving up on the patient: “there are opposing views from other medical units, believing initiating discussions on end of life care means withdrawing care” (nurse). Comments like this spoke quite strongly to the lack of understanding around what EoL should be. Another nurse added: “we have a long way to go before dying with dignity becomes a reality in hospitals. Doctors are the most resistant at giving up”.

Death as medical failure. Death in some clinical settings was seen as an event to be avoided, a defeat, and there was a great reluctance to give up treatment. A nurse said “there is a continuation of life saving therapies regardless of impending end stage conditions when working in oncology”. Another nurse said: “If you want to pass away please don't come to the hospital most doctors will not let patients simply pass away even if it is the patient's wish and they have an advance care directive”.

A number of respondents further commented that discussing death was a taboo topic: “No-one is allowed to die anymore...it has almost become a dirty word!! As is often said in ICU circles...we tend to be more human with our pets than our loved ones” (specialist). Death in the clinical setting seemed a medicalised rather than natural process, and an attitude of death as medical failure was considered a significant impediment to communication. However, a nurse normalised death: “Everybody dies it is a part of life. The population is aging and there is a point where it is impossible to keep people alive indefinitely”.

Care goal transition. Difficulty reaching agreement among medical teams, and with patients and their families, and for accepting the prognosis of death, impaired transitioning care to comfort measures.

Often other clinicians who make unrealistic plans with unrealistic relatives and offer medically futile treatments that are often also unrealistic, are a major obstacle in transitioning patients to best supportive care and a major cause of frustration and

relative dissatisfaction. E.g. patient with end stage COPD offered intubation [by other specialist] when ICU unwilling to honour request (specialist).

Therefore, the timing and place of EoL discussions became problematic. “Doctors are not having the discussion with patients early in their disease about at which stage they want to stop” (nurse). Discussions and planning that had taken place even prior to a terminal diagnosis often made broaching the topic much easier for both patient families and other doctors. “The importance of an Advanced Care Directive cannot be stressed enough; it is at times an inroad to commence an end of life discussion with a relative/resident” (nurse)

Recognising contextual differences with patients and families. Respondents also recognised unique and contextual differences such as the patient’s individual disease stage and family sensitivities at that time, and how these could constitute challenges for communication. Acute or critical events often precluded the opportunity of engaging in discussions with patients: “the patient is often not in a position to converse when I see them for the first time” (specialist). This may also occur where, for example, end stage illness has progressed or treatment such as sedation or analgesia has impaired the patient’s cognitive abilities: “patients’ lack of capacity to understand information due to illness severity” (specialist). Frequently, discussions need to take place with family members and this can be a source of conflict over appropriate treatment decisions. A nurse said, “it’s more difficult when there is family pressure to continue treatment”.

The need for cultural competency, including an ability to cater for language diversity, were also common impediments to initiating effective discussions. “there is a need for training health care interpreters to understand the nuances of translating this information” (specialist).

Lack of formal training and low confidence. The difficulties in engaging patients and families in discussions elicited many additional responses that identified a lack of

confidence and skill, and directly implicated insufficient training in EoL communication. Junior nursing staff were sometimes considered ill-equipped to discuss EoL wishes with patients: “Many young nurses have never come across a death/dead body before nursing, let alone have to talk to a patient about EoL wishes” (nurse). Another nurse conveyed a sense of being alone when working with “medical officers who are uncomfortable initiating these conversations and not supporting us”. It appeared that nurses were often required to initiate EoL conversations but noted the lack of training opportunities: “There is no formal training during university for nurses on how to have end-of-life conversations and also no formal training once employed in the ICU unless you attend an ADAPT organ donation course through the donate life network” (nurse).

An unhelpful system. Organisational and systemic factors often worked against engaging in effective EoL conversations.

Our systems work against us when we try to provide this necessary part of care in EDs. Interruptions, lack of time to sit and listen to patients, lack of private places to talk, lack of a pre-existing relationship with the patient and family on which to base discussions, a pervasive feeling of mistrust that the talk is just a vehicle to document NFR [not for resuscitation] in the notes (specialist).

Although the clinical context of EDs and ICUs are not well set up to initiate EoL discussions, it was also noted that EoL conversations are not just a singular event: “it is not a one off conversation but an ongoing dialogue that is revisited as each change occurs” (specialist). Patients and families, and their clinical team, need time to effectively consider the information being discussed and have the capacity for ongoing discussions. “It’s bad not having enough time to remain with the patient after the conversation has concluded - often there are more questions or discussion needed some time later” (nurse).

The role of initiating EoL conversations was also contingent upon factors of seniority: “too junior, my senior should initiate those conversations” (specialist trainee); and also not considered their role by all medical units: “inpatient specialist teams frequently do not discuss ‘end of life’ with patients/families who clearly warrant this discussion. Often, it seems to be left to the ED when the patient is in crisis” (specialist).

Facilitators of EoL Discussions. There were three key themes that described the qualitative data in this area. Communicating and collaborating; Developing rapport and relationships; and Skilling up to engage in EoL discussions. The last key theme was further described by a subtheme of Student training and mentoring.

Communicating and collaborating. When respondents were asked as to what would better facilitate EoL discussions, the most central aspects were communication and collaboration within and across teams. Consistent information was considered crucial with a specialist saying “we must ensure all MDT’s [Multidisciplinary Teams] communicate the same information”. This could be facilitated by strong cross-disciplinary collaboration: “It has to be a total team effort, sometimes in ICU different teams are on differing pages and not aware of the communications between the patient and family re end of life discussions” A nurse especially emphasised that “medical teams need training in limiting treatment, and how that is communicated to the patient, and having a holistic approach”.

However, effective EoL discussions were considered best if grounded in the community and with strong primary care involvement. “The GPs [General Practitioners] should be included as that is where the conversation needs to start with all patients” (specialist). Such pre-emptive education and primary involvement could diffuse potential conflict and inappropriate care. “The community needs more information, GPs need to take a bigger stake in this, before the patient gets into trouble and presents to an ED and gets put on the merry-go-round of acute care for a non-reversible outcome” (nurse).

Developing rapport and relationships. A large number of respondents noted that difficult discussions around EoL care can be strongly mediated by developing relationships and especially rapport. “I realise that how I communicate is about the quality of the relationship that I have with patients and family members - and quality takes no extra time as it's about connection” (nurse). Also developing strong relationships as early as possible was considered particularly advantageous:

Building a relationship of open communication is really important. The earlier end of life discussions are raised, the more prepared family and patients are on what to expect when the time comes. Also they have more time to deal emotionally with the thought of end of life (nurse).

Understanding the patient's illness better informs discussions with patients but relies on better communication among staff: “having adequate information available about the patient's illness and prognosis which means better communication between health professionals” (nurse). Expertise with EoL discussions can be gained through previous experiences. “Talking with families who have been through this experience and what they liked to hear from the staff” (nurse). But the clinical context exerts a strong influence on how EoL discussions can be initiated: “we need a supportive institutional culture” (specialist).

Skilling up to engage in EoL discussions. Clearly, those who had more experience initiating EoL discussions found them less aversive. They had developed helpful understandings on EoL. A large number learnt through exposure on the job: “years of experience and realising that we can't save everyone but we can make the end more comfortable for all concerned” (nurse). Others regarded life experience as important for learning: “my experience and ability to have end-of-life conversations with patients is self-taught and developed through having conversations with patients before and through life

experience” (nurse). However, expertise developed through experiences often takes time, and new health professionals may not have acquired these. Respondents provided many insights and suggestions for training that could develop skills to engage more effectively in EoL discussions.

The idea of role play emerged strongly. A nurse said: “We need to take ownership of these issues, role play and model discussions with junior staff” (nurse), while a specialist commented that “an experiential workshop using actors would be helpful”. Another nurse suggested: “filmed simulation practice in a closed group. This method often improves the mastery of other clinical skills too”.

Other respondents suggested convening meetings and workshops within teams as beneficial to skill development. A nurse recommended “multidisciplinary meetings with treating teams, nursing staff and social workers to understand each other’s roles and work through case examples”. Some were already offering similar training: “It is something I regularly do [discussions] and am very comfortable with as an ICU trainee. The Organ Donation team runs an excellent 2 day face to face workshop which has proved invaluable to me for this skill” (nurse assistant).

We also noted that the concept of mentorship was regarded very highly by respondents. Typical comments included: “there is much to be learned from the experience of others” (nurse) and “need to have a term shadowing a palliative care specialist” (specialist trainee). But the idea of who provides mentorship was also recommended to be very discipline specific: “I don’t think Palliative Care could or should mentor acute care physicians in decision-making. Treatment decisions usually predate Pall Care referral. I would prefer to be mentored by senior colleagues in my own specialty” (specialist). Other areas of suggested education were aimed at inter-clinician communication but also taking on more of an advocacy role for their patients: “Skills are also needed for clinicians to

communicate clearly with other colleagues in terms of advocating for the patient's end-of-life needs and wishes; sometimes this is the biggest barrier" (specialist). It was also recommended to educate patients more directly: "Brochures with basic minimal literature for patients and families as reference assists as they often do not absorb the discussion you have with them and they then have a reference" (nurse).

Student training and mentoring. Many respondents, particularly nurses, considered training for communication skills vitally important in student education. They provided comments like: "This is an essential component of training for nursing and medicine. This should be a mandatory curriculum item that is trained, practiced and assessed" (nurse) and "early exposure to these ideas prepares novices for developing skills" (nurse). Death should also be normalised: "Death is a fact of life and end of life discussions should be the norm rather than the exception – very important part of their training" (nurse).

The role of observation as an educational strategy was frequently noted. One nurse said: "medical students, interns and registrars specialist trainees should be taught how to have these conversations and be encouraged to sit in on such discussions to make this easier in their future practice" (nurse) while a specialist commented: "the more skills each person has the better they are prepared for the real experience. Witnessing an experienced colleague helps".

Providing a safe environment was considered very important: "make sure trained and experienced staff are available on clinical workplaces to support" (nurse). However, a small minority also provided contrary views: "I think that they have enough to try to deal with, without adding this emotional topic" (specialist).

Discussion

Our thematic analysis of the qualitative survey data allowed us to develop a deeper understanding of how senior and junior doctors and nurses experienced EoL discussions in Australia. They shared their knowledge on the facilitators and challenges they encountered, and offered suggestions for improving EoL communication with patients and their families, and also among health professionals.

Recognition that physician-patient communication at EoL is suboptimal is not new (Morita et al., 2004), and our results confirm that it remains suboptimal today despite multiple calls from others in the previous decade for it to be addressed. Recent studies found that only a third of residents felt comfortable initiating such discussions (Siddiqui & Holley, 2011) and only 12% of clinicians reported having regular end-of-life discussions with heart failure patients but over 30% of these stated their low levels of confidence in the area (Dunlay et al., 2015). Our respondents similarly reported discomfort and a lack of confidence around discussions, especially for younger staff, and they often mentioned that it was unclear whose role it was to initiate discussions. The medical culture of avoiding death and measuring mortality as a bad outcome in hospital quality of care indicators perpetuates this communication drawback. The patient safety industry does not yet encourage the inclusion of “dying safely” (Cardona-Morrell & Hillman, 2017) as a metric, but this could help normalize the acceptance of death as a natural outcome of old age and advanced chronic illness.

Our findings further support those of a recent mixed-methods, anonymous online questionnaire of 1,040 multi-specialty trainees caring for seriously ill patients in the USA health system (Periyakoil, Neri, & Kraemer, 2015). They found EoL discussions challenging and similar barriers emerged from the analysis of their open-ended responses. These included family requests for withholding prognostic information from patients; family requests to continue futile treatment, patient’s and families’ limited health literacy to understand complex concepts; cultural differences in expectations in conveying information and

decision-making; doctor's insensitivity of cultural beliefs, values and practices; and lack of training and time to communicate appropriately.

Some of our respondents mentioned lack of cultural competency as a barrier for optimal EoL communication. In multicultural societies like Australia, developing cultural sensitivity in EoL discussions is an ethical imperative. Patients from the Asia-Pacific region frequently report a greater preference for life-prolonging measures (Ohr, Jeong, & Saul, 2017) which contrasts with some from Caucasian backgrounds who are more likely to have do-not-resuscitate and do-not-hospitalise orders (Lu & Johantgen, 2011). Chinese communities prefer shared family decision making over more autonomous decision making as espoused by Western cultures (Bellamy & Gott, 2013). Where healthcare professionals recognise and acknowledge the importance of religion in the life of a patient, there are higher rates of hospice use, fewer aggressive interventions and fewer ICU deaths (Balboni et al., 2011).

Regardless of culture, however, patients and their families will experience EoL uniquely and their beliefs and readiness to engage in communication need to be considered by their doctors and nurses. Problems present around patient readiness for information, while systemic factors such as the time required for EoL discussions, as noted by our respondents, are common (Dunlay, et al., 2015). When patients and families do not accept a prognosis of dying there are low referral rates to hospice care (Moss, et al., 2005). Sometimes doctors and families perceive a sense of abandonment when hospice or palliative care is presented as an option (Back et al., 2009; Collins, McLachlan, & Philip, 2017).

Clinicians' lack of certainty of when a patient is dying and lack of understanding of the dying trajectory is another recognised problem in routine care (Cardona-Morrell & Hillman, 2015; Forbes, 2001; Watson, Hockley, & Dewar, 2006) and can often result in futile treatments being administered (Palda, Bowman, McLean, & Chapman, 2005). The lack of a

timeframe, even with inevitable uncertainty, makes planning of transition from active treatment to comfort care difficult (Coombs, Addington-Hall, & Long-Suthehall, 2012). This often leads to incomplete, suboptimal and rushed EoL treatment discussions at times of emergency or terminal hospitalisations (Anstey, et al., 2015; Jones, Moran, Winters, & Welch, 2013).

Sometimes doctors avoid being specific, and instead opt for a wait-to-be-asked approach before offering information as they believe patients increasingly expect greater prognostic certainty than is possible and making a prognostic error may result in patient loss of confidence (Christakis & Iwashyna, 1998). Our respondents also noted that discussions often do not take place early enough in the disease trajectory or before a critical event. It is difficult understanding the expectations of patients and their families when there is little time to develop a relationship or rapport. A number of our respondents suggested greater primary care involvement, where the GP should be part of the medical team as they often have intimate knowledge of individual patient and family circumstances.

Further delaying the transition to less aggressive models of care, our respondents stated that pressure from colleagues to continue treatment and not give up was a barrier to good EoL care. They also identified the discrepancy between the opinions of doctors and nurses and within medical teams regarding the point where palliative care should become involved in patient management. This conflict is not uncommon across diverse health systems (Coombs, et al., 2012), and particularly in ICU where death is sometimes perceived as a failure (Anstey, et al., 2015; Trankle, 2014). This was a notably strong theme in our data also, where doctors and nurses regarded discussion of dying as a taboo topic despite the fact that they suggested that death should be normalised as a natural process, particularly for new and inexperienced staff, and in student education.

Moreover, care goal transition should also include discussions for the place of dying and death. An Australian study found that almost all patients who were suitable for palliative care were, in fact, admitted to hospital in their last year of life (Rosenwax et al., 2011). Over 60% of them were in hospital on the last day of their life. This is despite information being available for several years that Australians over the age of 60 years prefer home (56%) or hospice (13%) as their place of death, rather than hospital (29%) (Foreman, Hunt, Luke, & Roder, 2006).

Many of our respondents regarded the presence of an advance directive as a facilitator for the EoL discussion. Others have also seen ACDs acting as an ice breaker for EoL conversations (Hilden, Louhiala, & Palo, 2004). Research has shown doctors working with geriatric patients felt decisions were easier to make and they often changed their decisions to align with living wills that were in place (Schiff, Sacares, Snook, Rajkumar, & Bulpitt, 2006). How this applies for younger doctors, or translates to other populations where death is unexpected through critical or acute events, is unknown. Additionally, a recent systematic literature review could not determine whether ACDs actually enhance engagement in EoL discussions (Lewis, Cardona-Morrell, Ong, Trankle, & Hillman, 2016). It is also important to be aware of the risk that assuming the conversation is not required if there is an ACD because living wills and treatment preferences can change after ACDs are formalised (Schwartz, Merriman, Reed, & Hammes, 2004).

In our study, junior staff reported feeling greater discomfort in EoL situations and the need for more training in communicating bad news than older more experienced staff. This is consistent with other studies (Haslam, King, Pinckney, Sunar, & Baines, 2016; Sturman, Tan, & Turner, 2017). On the job experience also appears to have been a facilitator for staff to engage more successfully in EoL discussions. Nonetheless, even experienced staff did not discount the emotional impact of EoL discussions with some claiming they continued to

reflect on these interactions for some time later. Some further noted their psychological attachment to particular patients which can result in compassion fatigue and burnout (Abendroth & Flannery, 2006; Aycock & Bolye, 2009).

Engaging in EoL communication can be highly stressful, especially for those not well trained or experienced. It is important to consider the emotional and psychological well-being of staff to ensure high quality EoL communication and care can be provided. High rates of stress could lead to staff withdrawal, mistakes being made and the risk of personal harm. A large survey of over 14,000 doctors in Australia recently revealed rates of stress, mental illness and suicidality, particularly for those who were younger (<30) and female, being far higher than rates in the wider community (Beyond Blue, 2017).

Although our respondents did not specifically mention how they dealt with aversive experiences, many may have developed particular coping strategies (Ciccarelo, 2003) but this may not be the same for younger inexperienced staff. If staff are withdrawing from or avoiding potentially uncomfortable discussions which are crucial to good EoL care, then debriefing and support mechanisms may need to be more strongly instituted in secondary and tertiary EoL settings.

The finding that younger staff felt less confident than older medical and nursing staff confirms the views of most specialists and older nurses that skills on communication of sensitive news come from experience. In the Australian health system the unwritten rule implies that doctors are charged with the task of initiating the conversation, and nurses are involved in continuing the conversation. Similarly, our results showed that junior doctors defer the initial conversation to their more senior colleagues. However, respondents reported a lack of clarity on this role with a number of nurses being required to initiate conversations. In these cases nurses felt unsupported by doctors. Both groups reported high confidence in

communicating bad news but the experienced nurses felt junior staff needed help in developing skills for this.

Support for undergraduate training in managing EoL discussions by our respondents was mixed as many perceived the skill as something to be learnt from experience on the job. But a lack of rotations in EoL care in the medical curriculum is also a factor identified by a USA study on 62 residency programs which found that only 9% of medical students and 16% of residents had completed a rotation in EoL care (Sullivan, Lakoma, & Block, 2003). After their rotations, these students and residents still felt inadequately prepared to deal with discussions on cultural issues at the end of life and spiritual beliefs. Over a decade later, our study indicates that the training gap still exists for junior doctors, and is consistent with a recent report that palliative care competencies are given minimal classroom time for students while other conditions received far greater attention (Horowitz, Gramling, & Quill, 2014). Training in medical interviewing around suffering and goals of treatment, basic pain and symptom management, communication skills and team work would be a good step in the right direction (Chiu et al., 2015; Horowitz, et al., 2014).

Others have found that “compassionate care training” in undergraduate years improves truth telling, and discharge planning and decisions around home care (Shih et al., 2013). Using an integrated care pathway also helped nursing home staff recognise the dying patient and improved their confidence in explaining the dying process to relatives (Hockley, Dewar, & Watson, 2005). The use of continuing education on communication, workshops and train-the-trainer programs for EoL capacity building has been promoted before by others (Levinson, et al., 2010) but our respondents also noted strong value in role playing strategies, and observation such as shadowing a more senior staff member and receiving their mentorship. Finally, the establishment of consistent relationships with patients and their families was perceived to create and maintain confidence because individual needs could be

better considered. Family meetings in hospitals provided these opportunities for discussion and feedback. There is scope for younger staff members to learn by attending case conferences with patients and their families, and the medical team (Arnold et al., 2015).

While fears and discomfort on EoL discussions are prevalent, effective EoL discussions can have rewarding benefits for the patient such as receiving less aggressive care and fewer interventions at the EoL, earlier hospice referrals, better quality EoL and better bereavement adjustment for families (Mack et al., 2012; Wright et al., 2008). Indeed, most of our respondents considered effective EoL discussions particularly worthwhile despite the emotional burden they sometimes experienced.

A major strength of this research is that our clinical staff respondents covered doctors and nurses of all levels and ages working in hospitals, aged care and primary care. We particularly targeted the occupations most likely to deal with end-of-life (ICU/PC/ED and aged care nurses and doctors). Their suggestions to enhance end-of-life communications are drawn from their experience and are highly relevant to Australian clinical settings.

The main limitation of this study is that not all clinicians read emails, have twitter or Facebook accounts and they may not open profession-specific magazines received by post, hence our sample may have been affected by selection bias. We used many advertising strategies to recruit participants and offered face-to-face surveys in hospitals but at conferences, they may not have attended the session where the survey was advertised, or may not have had immediate access to a device for online participation. We may have missed respondents in rural or remote areas who did not have access to email or did not attend conferences, and were not aware of the online survey. It is important to consider that these areas may have a greater primary care emphasis with GPs providing EoL and acute care, and only transferring patients to larger city hospitals when care is beyond their capacity. It is reasonable to also assume they would know patients and their families much better since

there are no large corporatized medical centres in these areas where patients could see many different practitioners and where the GP workforce may be more transient. Relationships and rapport would be strongly established in rural and remote areas and may mediate the aversive nature of discussions. This survey may not have included the views of many of those professionals.

Although, our participants provided much information, their responses in many cases were relatively brief. This is often the nature of survey based approaches but such an approach allowed us to engage with a large number of participants. An opportunity to conduct in-depth interviews with a smaller number of participants may have illuminated the phenomena further, and could be flagged for future research.

Further areas for research include investigating the feasibility of addressing the persistent health system barriers still mentioned by respondents (unhelpful health system). This could be done by evaluating the impact of GP involvement. They may be beneficial as they are well placed, have more time and opportunity for repeat discussions, and have intimate knowledge of the patient and their family. They could provide important insights as part of the larger management team. Similarly, evaluating potential new models for EoL discussions if hospital doctors are uncomfortable or feel a sense of medical failure, and also investigating the effectiveness and acceptability of engaging senior nurses in initiating discussions may be helpful. They are the primary source of communication in hospitals with patients and families and many nurses reported being comfortable doing so, but nurses have often been precluded in the past because this was seen as the domain of doctors. Finally, examining the effectiveness of early on-the-job coaching in end-of-life communications by different specialist groups could shed some light on the details of domains to include in the discussion, and patients' satisfaction with its quality and timeliness.

Conclusions

In sum, senior ICU, ED and PC doctors and nurses have frequent exposure to dying patients and, unlike their more junior colleagues, generally feel confident about communicating bad news. However, this research has found that on a more general level in hospitals there is still a reluctance to discuss issues related to the EoL. Our key themes noted particular challenges in gaining consensus among medical teams, and with families, on treatment decisions. Some of these issues are related to the pervasive perception of death as a medical failure, reduced cultural competency, the absence of advance care directives on admission, and health system pressures such as limited time to make urgent decisions on behalf of patients without prior in-depth knowledge of their history or preferences. All of these factors potentially impaired appropriate care goal transition. The ability to develop relationships and rapport, and working more collaboratively, were regarded favourably by our participants.

Efforts in developing further training approaches, especially around delivering sensitive news, were perceived as more appropriate for junior staff. The focus for experienced staff should be on reducing uncertainty, perhaps through greater team consultation but also establishing a care plan that considers agreed approaches for care according to the needs and values of the deteriorating patient. Similarly, interventions to foster early discussions and address health system barriers are also still needed; as is engaging with the public in identifying the readiness of patients for knowing their true prognosis, and families in accepting open communication of this sensitive topic.

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